

March 14, 2025

State Representative Abdelnasser Rashid 242A-W Stratton Office Building Springfield, IL 62706

RE: Oppose House Bill 3041 Unless Amended (Illinois Data Privacy and Protection Act)

Dear Representative Rashid,

On behalf of the Illinois Society of Pathologists (ISP), representing pathologists practicing in hospitals, academic hospital centers, and independent hospitals across the state, we have strong concerns regarding the inadvertent impact of House Bill 3041 on the practice of medicine.

We are in strong opposition unless amended to House Bill 3041, which establishes the Illinois Data Privacy and Protection Act prohibiting "covered entities" from collecting, processing, or transferring covered data beyond certain parameters and requiring certain policies, practices, and procedures as it pertains to such data. The current definition of "covered entities" implicitly includes pathologists and clinical laboratories involved in the diagnosis of Illinois patients.

We are understanding the intent of HB 3041 is to increase privacy protections for Illinois residents by restricting the collection, sharing, and sale of sensitive personal information as encompassed in the bill. However, the purview of this bill should not include the practice of medicine, laboratory testing or medical genetic testing and other health care activities as these areas are already subject to rigorous regulation, including prohibitions on disclosure and robust privacy protections under the federal Health Insurance Portability and Accountability Act [HIPAA] of 1996.

Notwithstanding federal law regulating privacy of medical information, including diagnostic genetic information, the bill addresses under Section 15 (3) (C) and (E) transfer of medical genetic data:

(C) In the case of the transfer of genetic information, the transfer is necessary to perform a medical diagnosis or medical treatment specifically requested by an individual, or to conduct medical research in accordance with conditions of paragraph (10) of subsection (b) of Section 10...

(E) To prevent an individual, or group of individuals, from suffering harm where the covered entity or service provider believes in good faith that the individual, or group of individuals, is at risk of death, serious physical injury, or other serious health risk.

However, the aforementioned provisions do NOT explicitly exempt all information collected under the HIPAA. Within the confines of Section 10 (b) and Section (15) (C), pathologists who routinely collect, process, or transfer sensitive health care data may be at legal risk without additional informed consent from the patient.

Pathologists perform testing, including genetic testing, to establish diagnosis, without the legal impediment of additional consent of the patient during the collection, processing, and transferring of patient health care information. The contemplated limitations in the legislation to collect, process, or transfer covered data, in the paramount medical interest of the patient, including sensitive health information for individuals undergoing medical diagnosis, places pathologists, and other physicians, at legal risk of determining what patients are at "risk of death, serious physical injury, or other serious health risk" (Section 15 (3) (c)) to waive such requirements, thereby imposing administrative burdens and legal risks to pathologists routinely performing the practice of medicine.

Additionally, the bill implicates pathologists and clinical laboratories by imposing a number of administrative burdens under Section 20 (privacy by design), Section 30 (transparency), Section 35 (individual data rights), Section 40 (right to consent), Section 45 (data protection for children and minors), Section 55 (data security and protection of covered data), Section 65 (executive responsibility), *inter alia*, without robust and appropriate exemptions.

Of high concern, Section 35 ("Individual Data Rights") permits an individual to 'delete' covered data, under certain conditions, which is directly contrary to the legally responsible and ethical practice of medicine and does not appropriately shield pathologists and clinical laboratories from liability and administrative burden.

"(3) delete covered data of the individual that is processed by the covered entity and instruct the covered entity to make reasonable efforts to notify all third parties or service providers to which the covered entity transferred such covered data of the individual's deletion request; "

The bill includes stringent enforcement provisions under Sections 75 and 80 by the Attorney General and individuals, *et al.*, potentially subjecting pathologists and clinical laboratories to legal risk and financial penalties. Pathologists and clinical laboratories should not be subject to legal liability for the routine provision of health care services provided to Illinois patients. **Accordingly, the following amendment is needed to exempt pathologists and other physicians from the purview of this legislation by expressly excluding from the definition of a "Covered Entity" as follows:** 

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(4) a person or entity that is collecting, processing or transferring covered data that is subject to the Health Insurance Portability and Accountability Act of 1996 and related regulations

Across the myriad of state data privacy laws and other Illinois legislative proposals filed, there has been a universal understanding of the public policy need to explicitly exempt health care information aggregated, shared and synthesized in the health care setting for purposes of patient diagnosis, treatment, and care. This exemption ensures that physicians like pathologists, health care facilities, and clinical laboratories are not included within burdensome and duplicative state privacy requirements as it pertains to sensitive health/genetic information already regulated under federal law.

Accordingly, we urge you to amend the bill to robustly exempt physicians and protected heath information collected as defined under HIPAA from all contemplated requirements of this legislation. For these many reasons, we urge your opposition to the bill in its current form, unless amended with the proposed HIPAA exemption for covered entities subject to this purview of this legislation. Thank you for your consideration of our concerns.

Sincerely,

Tushar Patel, MD Illinois Society of Pathologists President

cc: Erin O'Brien, Illinois State Medical Society
Barry Ziman, Director, Legislation and Political Action, College of American Pathologists